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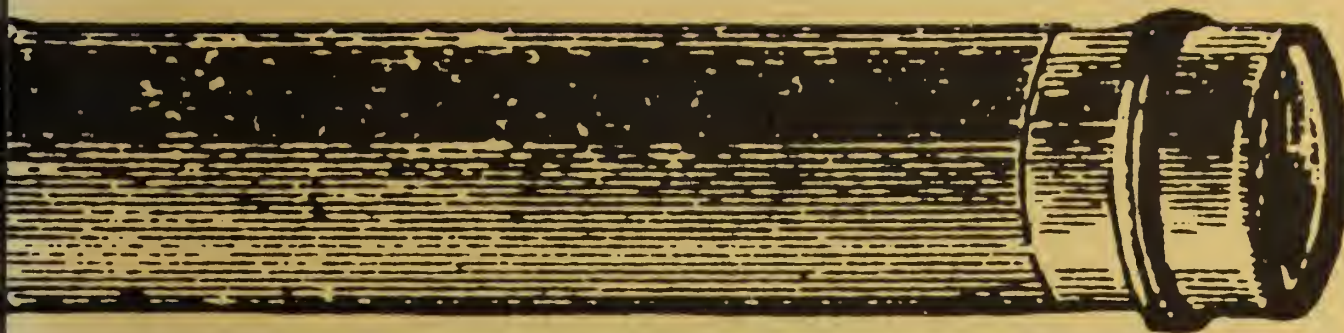


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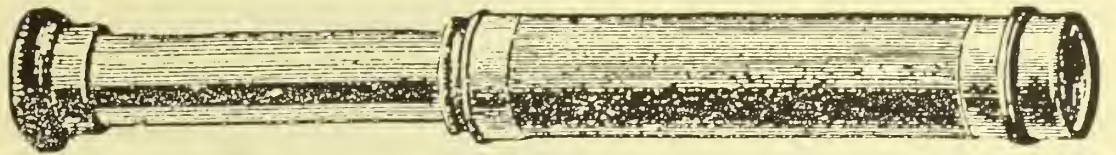
Charting the Course

*What Massachusetts'
Mentally Retarded
Citizens Need
1986 - 1996*

The Report of the Long-Range Planning
Task Force on Mental Retardation

June, 1986

Charting the Course



The Task Force wishes to acknowledge the assistance of the Commonwealth of Massachusetts in producing this report.

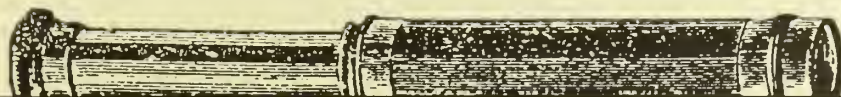
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We Are Family

Mental retardation involves families in the broadest and deepest ways—families encouraging the growth of their retarded child; the retarded person living in a family-like home; the broader community ensuring the human rights of the individual with retardation. As members of this extended family, each one of us is involved with and responsible for those in our midst who happen to be mentally retarded.

Like all families with a goal worth working for, this family needs to plan: to assign tasks, share responsibilities, evaluate results. Everyone has a role to play and a contribution to make.

Families want the best for their members, and they set their priorities with the most important needs in mind—education, housing, health, nutrition, security, opportunity, recreation, growth, love. Although families want to protect their vulnerable members as they mature, they also know that each person has a birthright to the highest degree of personal freedom and choice.

In the end, families must encourage their members to pursue their own lives. Adults who can make their own choices and also rely on a network of social supports are truly independent and interdependent.

The Long Range Planning Task Force on Mental Retardation presents this report to the Executive Office of Human Services and the Department of Mental Health in this light:

How can we best help those members of our "family" who are mentally retarded toward participation and independent decision-making?

We invoke the larger family because individual families cannot do the job alone. Before the advent of early intervention, special education, community programs, and improved state schools, individuals with retardation were often hidden from sight in their homes or overcrowded institutions, consigned to a twilight world of shame and stagnation. Only active public advocacy has made respect for retarded citizens—and the

development of adequate services—components of contemporary social policy.

The family that is Massachusetts is at an historic crossroads in the way it views and deals with its members who are mentally retarded. Many of our mentally retarded citizens are now receiving first-rate attention; many others are not. Some of the Commonwealth's programs are exemplary—the end result of thoughtful planning and wise investments. In other cases, though, real needs and real people have "fallen through the cracks," overlooked in the press of administrative and legislative action, federal Medicaid policy, and judicial mandate.

Our challenge over the next ten years will be to make high-quality services available to all who need them—building on what we have learned, preserving the best of existing programs, and creating new opportunities where they are needed. The Task Force has considered not only what persons with mental retardation need and want, but how to support their families, teachers, employers, and neighbors.

Our goal, in short, is to make a reality of "Opportunity for All."

If we get to the point where my little Jennifer is 22 years old—and then necessarily we rely on state services—if something isn't in place that's meaningful and has dignity to it, there are going to be a lot of angry parents out here.

—Parent

How the Task Force Operated

The Executive Office of Human Services (EOHS) and Department of Mental Health (DMH) asked a number of citizens in August, 1984, to address a range of service issues surrounding the care and treatment of this state's mentally retarded residents. This Task Force—composed of parents, advocates, service providers, administrators, and professionals with a wide diversity of opinions—asked these questions:

- *How are needs currently being met?*
- *How is the population changing?*
- *What gaps in service exist now?*
- *What new or enhanced programs are needed for the future?*
- *Which other kinds of residential services will be needed?*
- *How should the state organize its administrative support?*
- *How can funding sources be utilized more effectively?*
- *How can the quality of services be monitored and assured?*
- *What is the appropriate future role for state schools?*

Broadly speaking, the Task Force's mission was to examine the current system's programmatic, organizational, and financial structures, and to recommend forward-looking improvements. To that end, the Task Force created five committees, all composed of volunteers and staffed by DMH/MR personnel:

- Administrative Organization
- Community Services
- State Schools
- Funding
- Quality Assurance and Monitoring

Each committee met regularly over the past year and a half, taking testimony, evaluating research, studying proposals, and visiting programs. In June, 1985, the Task Force held a series of forums across the state to describe each committee's mission and to invite suggestions from all parties, including clients, parents, professionals, advocates, academics, administrators, and service providers.

These comments, questions, and concerns (some of which are quoted in the margins of this report) were incorporated in the next series of committee deliberations, which in turn led in February and March of 1986 to a second round of statewide forums attended by hundreds of people. The detailed reports finally submitted to the Task force Steering Committee are the result of thousands of person-hours of work—and years of experience.

Beyond the Consent Decrees

In 1966, after two years of research, the federally-funded Massachusetts Mental Retardation Planning Project issued a comprehensive survey and 10-year plan. Its recommendations were finely detailed, urgently stated—and often not implemented. Sadly, twenty years later, we find ourselves focusing on many of the same unmet needs.

In the early 1970's, the lack of state action led several groups of parents successfully to sue the Commonwealth of Massachusetts over unacceptable conditions and deteriorating facilities in the five state schools—Belchertown, Fernald, Monson, Wrentham, and Dever—where over 6,000 of the state's mentally retarded citizens then lived. Recognizing that much had to be done, the state and the plaintiffs negotiated a series of agreements.

The ensuing “consent decrees” mandated compliance with a series of standards which, over 15 years, have brought enormous improvements in the schools' quality of life. Staffing levels are among the best in the country (nearly 1:3 staff:client ratio); buildings are thoroughly renovated; medical care is vastly improved.

Most important, the required Individual Service Plan (ISP) for each school resident has provided accurate assessment, customized planning, appropriate services, and professional accountability. In general, parents of the schools' residents are proud of the dramatic turnaround.

The consent decrees also sparked Massachusetts' participation in the national trend toward “de-institutionalization” of mentally retarded citizens. A panoply of small, client-centered, community-based programs has grown up to meet the needs of those leaving the state schools (2,500 since 1975), and of some who never lived in the schools: home-like residences and innovative housing arrangements; vocational training centers; supported and competitive work in the community; respite and on-site care for families whose retarded members live at

home; and transportation assistance to state-funded day programs.

Due to the consent decree blueprint and a vigorous state economy, Massachusetts is unusual in that funding has grown for both large-facility and community-based programs. Still, in 1986, too many of those who need services—some only occasionally, others part-time or full-time—are not receiving them, or are receiving inadequate or inappropriate services. More than 3,000 retarded persons are on DMH's service waiting list, 200 more than two years ago, and the need continues to grow.

Children are born every day with mental retardation of varying degrees of severity (see box on “Facts and Figures”); retarded young adults turn 22 years of age and lose their eligibility for special education programs; elderly retarded citizens, living longer than ever before, require specialized help.

The world of mental retardation, fortunately, has not stood still since the 1966 report. We know far more now about the productive potential of retarded persons, and most families assume the goal of independent or semi-independent living. A developmental model has replaced the custodial one, and the best programs enable the highest degree of personal choice for those who are retarded.

As a state, we have taken steps in the right direction, yet much remains to be done. We have learned lessons the hard way, innovated because we had to do better, but we have not always succeeded in putting individual needs before bureaucratic rigidity. As we disengage from the consent-decree era in the coming months and chart our own course, the Commonwealth cannot lose its momentum. We owe our mentally retarded citizens no less.

This report, a distillation of the five full committee reports, reflects the Task Force's tenor and highest-priority concerns. [The complete reports, which include supporting

The question arises at some meetings, “Where are the parents?” We are here, working diligently to care for our retarded sons and daughters at home, hoping fervently that when we are no longer able to do so, there will be quality, funded programs available for them.

—Parent

detail as well as additional recommendations, will be on file and available from DMH.] We should emphasize that, although DMH and EOHS have cooperated with the Task Force and supported its operations, the group makes its recommendations as a wholly independent body.

As Massachusetts approaches substantial compliance with the consent decrees, policymakers and administrators have an unusual opportunity to reinforce positive trends and move toward meeting the Commonwealth's next challenge: full services for *all* citizens with mental retardation. We wrote this report to highlight those areas which need immediate and long-term attention to accomplish the goal.

How the Recommendations Are Organized

This report focuses on those areas where we feel both guidance and leverage are possible: guidance on sorting through the many options available, and leverage for the broadest impact on the portion of our citizenry who are mentally retarded.

For the purposes of this report, we grouped our recommendations and supporting arguments into four areas of inquiry:

1. **SERVICES:** How can existing services be made more accessible and equitable? What new services are required? What (and whose) needs are not being met by the system? How is the population changing? How should we monitor program quality and evaluate results? How can we better support families? How can we coordinate services for those whose needs cross agency lines?

2. **FUNDING:** How are funds being used? How might the sources of funds be diversified, and reliance on Medicaid lowered? Are there untapped potential sources of funds? How can we involve the private sector to a greater extent? How can funding be used to encourage programs which promote real work, real homes, and independent living? How can resources be allocated more equitably and flexibly?

3. **STRUCTURES:** What administrative organization will best support the delivery of individualized services to people with mental retardation? How should duties and responsibilities be divided?

4. **AWARENESS:** How can we raise community understanding of mental retardation, and acceptance of local facilities? Can we reduce the incidence of retardation?

TOUCHSTONES

Does (or will) this program. . .

- *Support families?*
- *Provide more choice for more clients?*
- *Represent a cost-effective way to spend funds?*
- *Promote real homes, real work, and real friends?*
- *Lend itself to accurate monitoring and evaluation?*
- *Deal equitably with all persons who are mentally retarded?*
- *Encourage external (community/family/ corporate) participation?*
- *Advance our commitment to comprehensive, consistent, adequate, appropriate, active, and least-restrictive services?*



Services

Because the availability and excellence of services determine the quality of life for many retarded people, this group of recommendations ranks highest. The term *services* embraces the full spectrum of potential needs: employment opportunities, residential and day programs, family supports, respite care, transportation, and medical care. The report's other grouped recommendations—on funding, structures, and awareness—all further the delivery of quality services.

Provide a continuum of appropriate, quality services in multiple settings.

Each aspect of this unifying theme is important. A *continuum* describes an unbroken range of services, available and accessible to the wide variety of those who need them. Although many individuals are mildly or moderately retarded, a small number are profoundly so [see "Facts & Figures" box]; some need only straightforward training to compete in the workplace, while others have multiple disabilities requiring specialized approaches; some confidently live in cooperative apartments, while others need the assistance of full-time residential support.

A continuum also suggests the changing needs for help and support which charac-

terize the lives of *all* people. What is an appropriate service at one life stage may be a hindrance at another; what is supportive during a medical crisis may be an unjust constraint the next week. Unless a continuum exists, clients tend to remain in the nearest approximate service pigeonhole, regardless of the appropriateness of its fit. Due to a lack of options, many retarded people are locked into overly protective programs which have outlived their usefulness.

A continuum guarantees that the next step in the path is always there, when and where it is needed, and that changing services are available in the same location, so that progress doesn't necessarily mean uprooting. Breaks in the continuum are identified here.

Multiple settings reflect this continuum. No single model of mental retardation service can—or should—deal with all needs. Housing, job, and education settings properly range from one end of the spectrum to the other; they exist in towns and in cities, on farms and in factories, in public and private schools, with relatives and with professionals. Like all of us, mentally retarded people want real homes, real jobs, real friends, and real choices—wherever they are.

Quality is an over-used word that nonetheless has no substitute. Unless the Commonwealth commits itself to rigorous quality in the delivery of these services, retarded people will be shortchanged. Quality—a function of design, implementation, staff development, evaluation, and caring—is a focus of this report.

Serve Mentally Retarded Persons Where They Live

Our objective is to enable mentally retarded persons to live as normal a life as possible. They cannot be dependent on services at a distance; the services *must* be delivered where they (and their families) can use them—in the local community, throughout the state, close to home.

Supporting people in their own homes and communities represents a philosophical and logistical shift from the past, when the state concentrated its service efforts in a few large schools. The families who chose, instead, to provide for their daughters and sons at home faced such issues as community acceptance, suitable housing for adults, training and work prospects, transportation, social opportunities—and paying the bills for specialized assistance. For the most part, they dealt with these problems alone.

As communities replace state schools as the typical address for retarded citizens, all of these concerns must now inspire action on the part of professionals, planners, and providers working with families and state and local governments. Detailed recommendations in each of these areas follow.

For families who support their retarded members at home, the growth in community-based programs is an aid but not an answer. The stress and responsibility of caring for a retarded child or adult can be considerable, but current state programs do little to reduce that pressure. In effect, the state's policy persuades emotionally and financially strapped families that, although they might prefer to provide the care themselves, they should place the retarded member in out-of-home, taxpayer-supported housing.

Consent-decree compliance has not helped two significant groups: (1) Middle-aged adults who have always lived at home, who may never have had educational and work services, and who will need supervised living arrangements when their parents can no longer help; (2) Children now in special education programs who face an abrupt transition into inadequately-funded adult services when their entitlements end.

These individuals and their families save the Commonwealth an enormous amount of money each year, yet supports to maintain the family unit are minimal, particularly when a child has outgrown special education programs. A modest expenditure of state funds for family supports would yield much larger savings over the long term. More families would choose to provide direct primary care if they felt confident that:

- they could obtain relief through professional respite care several hours a week or several weeks a year;
- specialized in-home care was available on a periodic or as-needed basis (not just during crises);
- good day programs such as supported work and day activity existed locally;
- adequate transportation to and from work existed;
- formal planning and support would ease the transition of leaving school, learning job skills, entering the workplace, and moving into a new home as parents aged or died.

Meet the Needs of All Mentally Retarded Citizens

More than 3,000 mentally retarded persons are currently on DMH's waiting list for residential, employment, or support services, and the list is growing. Many have been on this list for years, vainly attempting to obtain even minimal help from the state. Those without services need them as much as those with them; the inequity is a matter of timing, political astuteness, legal entitlement, client age, and location.

Although the waiting list substantiates an unmet need, it undoubtedly understates the true numbers. Many individuals are unaware of the list in the first place, are unsure how to get listed, or get lost in the maze of uncoordinated social services. We don't really know *how* many people need services, or even what types—the list provides little in the way of useful planning data.

We believe that all mentally retarded persons have the right to services, and that the waiting list is an embarrassment to a state which prides itself on an enlightened

My wife has a relative who spent 30 years in an institution, who is now back in the community, and is doing better now than she ever did before. I feel that services that are offered in the home or in the community benefit the people more than anything else.

— Advocate

I think they should leave it the way it is. They should leave the people alone where they are happy. I have been there 55 years, going on June, and all of a sudden they want us to get me out and I don't want to. I have good friends in Belchertown. I enjoy them.

—State School Resident

social policy. This is not meant to minimize the strides taken during the past twenty years or the success of services currently available, but to point out that the job is far from finished. Many who need help have been left out.

Simply put, we should *eliminate the waiting list*. This need grows more urgent daily, as:

- at least 600 persons with severe disabilities (most with MR) turn 22 years of age each year;
- a moratorium on admissions to the Dever and Wrentham schools has been in effect for ten years;
- 300 severely disabled children are in pediatric nursing homes because less restrictive programs are not available;
- abuse and neglect of some retarded persons is an unaddressed problem;
- few families with retarded children now consider or are provided the option of state schools;
- elderly retarded persons live longer now.

While it is clear that more numerous and better-funded community-based programs will be needed, much of the required service is a matter of relatively low-cost case-management, counseling, pre-crisis intervention, transition planning, respite, and other family supports. Services delivered under crisis conditions carry a far higher price, in both human and dollar terms.

Broaden Housing Options

While a move toward state-funded community residences is indeed taking place (from about 500 individuals in 1966 to more than 3,200 today) most of the programs have been designed for “class clients” (direct beneficiaries of the consent decrees) moving out of the larger state school buildings. Missing are a broader array of housing types for all mentally retarded citizens, covered by the decrees or not.

More than a dozen residential models, with varying staffing and service levels available, are currently in operation. In addition to the state schools, these include group homes, staffed apartments, cooperative apartments, community-based Intermediate

Care Facilities for the Mentally Retarded (ICF's/MR), specialized in-home and out-of-home care, and private housing.

Capital funding for ICF's/MR and “Chapter 689” housing projects (generally group homes and apartments) has been particularly strong recently and will soon provide more than 800 new places for mentally retarded persons, most of whom have never lived outside the schools.

Because compliance with the consent decrees is behind much of the new construction, though, two unfortunate consequences result.

1. Retarded persons who are not class clients receive little benefit from the new community housing funds. Even with the addition of 100 new residences, hundreds of people remain in need of residential services of one type or another. These include persons whose aging parents can no longer take primary responsibility, young adults who have graduated from special education/residential (Chapter 766) programs, persons needing occasional residential support, and persons with low-incidence or multiple disabilities requiring sophisticated supports.

2. Many of the new residences are owned, operated and staffed by the state, on state property (including some on the periphery of state school grounds).

These two drawbacks raise issues of equity and integration. We on the Task Force see the following characteristics as fundamental in superior housing programs:

- *Community-oriented*—staffed by local residents, operated by local providers, and supervised by area boards;
- *Home-like in scale and design*—sheltering a small number of individuals and blending into the surrounding neighborhood;
- *Open to all*—accessible to every mentally retarded person for whom they would be appropriate;
- *Focused on the person*—not designed in response only to available resources or existing models;
- *Adaptable*—changing with residents' growth, needs, and choices.

Only if housing programs turn into homes will towns come to accept and support the presence of persons with mental retardation; only in this way will mentally retarded

persons successfully integrate their lives into the community's. Locally-based housing programs have a unique capacity to generate community interest, trust, and involvement—in the form of volunteers and donations.

Cost-effectiveness is an admirable goal, but it has all too often resulted in a "cookie-cutter" approach to housing design. ICF's/MR, for example, are all built on a rigid, eight-bed model constrained by Medicaid regulations. The Task Force urges that all state-assisted residential programs be *real* homes which blend into their neighborhood settings and meet their residents' personal needs and preferences.

This lack of creativity in housing services is also expensive for the state. If, for instance, DMH offered services in homes or apartments bought privately (by families for those not needing a high level of support), these families would not be compelled to place their mentally retarded members in

publicly-funded residences to obtain aid. Again, more options and more flexibility benefit everyone.

Finally, we urge DMH to create a permanent Architectural Advisory Board to evaluate the design, construction, and modification of department-sponsored housing and other facilities.

Make Real Work the Goal of Employment Programs

If our experience since 1966 has taught us anything, it is that mentally retarded persons are far more capable of ordinary life activities, including regular jobs, than was previously believed. Current employment programs, however, tend to lock clients in at a lower level of work integration than is just, appropriate, or necessary. Of the 7,500 persons served, 28 percent are in "pre-vocational" programs (day activities and

Let me ask you this. If you had a son or a daughter who was severely retarded and you could no longer take care of him at home, where would you want him to live? Think about this, please.

— Advocate

THEME & VARIATIONS

Provide a Continuum of Appropriate, Quality Services in Multiple Settings

SERVICES

Serve mentally retarded persons where they live

Meet the needs of all mentally retarded citizens

Broaden housing options

Make real work the goal of employment programs

Pay competitive wages to attract and retain staff

Train and certify direct-care personnel

Remedy gaps in support services

Help individuals with additional needs

Coordinate inter-agency services more effectively

Improve the Individual Service Plan (ISP) process

Create a quality assurance function within EOHS

STRUCTURES

Create a Department of Mental

Retardation within EOHS

Support area-based service delivery with a three-tiered structure

FUNDING

Creative and diversified

Fair and flexible

Dependable and adequate

AWARENESS

Prevent the occurrence of mental retardation

Reduce the severity of mental retardation when it occurs

Build community acceptance and reduce isolation

The backbone of the service system is the direct-care staff, the people on the line. If we can only pay people ten to twelve thousand dollars a year to work with our people in the community, that system is going to collapse .

— Service Provider

habilitation), and 61 percent are in “sheltered” workshops. Only one retarded person in ten is employed on-site in a regular or training capacity. The number should be much higher.

Today's low-unemployment state economy offers an unusual opportunity to involve private-sector employers in integrated-work programs for persons with retardation.

These principles, we believe, characterize an enlightened employment policy for retarded persons:

- Funding decisions favor *real* work.
- Training is always in the least-restrictive setting possible, preferably in regular work environments, and focuses on private-sector “growth” occupations, such as clerical and service jobs.
- Individuals have the opportunity to express their preferences, follow their interests, and try different jobs—just as others do.
- People work where they can earn the most money and benefits—if they choose—and are not held back to boost a workshop's output rate.
- Social-skills training enables retarded persons to fit into work environments.
- Programs are located when possible near public transportation.
- Everyone who is or can be privately employed has a transportation coordinator to see that he or she can get to work.

Additionally, a U.S. Department of Labor rule now requires that, to qualify for a minimum-wage waiver, a workplace must segregate handicapped persons. We encourage the opposite, allowing mentally retarded persons in training to work alongside regular employees. Massachusetts should add its voice to national efforts to resolve a number of related Department of Labor issues.

Pay Competitive Wages to Attract and Retain Staff

Those with the most intensive day-to-day involvement with mentally retarded individuals are direct care personnel. Ultimately, their dedication and morale determine the

quality with which services are delivered, and their longevity in positions provides continuity and reassurance for clients.

Considering the importance, difficulty, and sensitivity of the work they do, the staff in most community-based programs are grossly underpaid—\$12,000 is an *average* (not starting) annual salary. As a result, staff burnout and high turnover rates are chronic problems in the field and create a sense of instability for both clients and parents.

Any effort to improve the quality of services at the delivery level must address the issue of staff compensation. We will not realize safe, stable, quality services until we have well-trained, qualified, and appropriately-paid staff. Massachusetts needs to fund vendor contracts at a level which allows for fair and competitive wages.

Remedy Gaps in Support Services

Support services are those which fall outside of housing and employment, but are the “lubrication” which enable many of the primary programs to operate at all. Retarded persons often require transportation services, for example, to get to a training center or a job. Support services such as family counseling, health care, companions and attendants, housing modifications and equipment, and recreation are equally valuable in easing the return of a person to community life. Properly delivered, they significantly reduce the incidence of crisis situations and enhance the quality of life.

Families and care-providers also need supports. Respite care—“time off” for families—is a fundamental service which ultimately saves the state money by preserving the family unit. Currently, though, workers and spaces for respite care are not always available when families need them. Because providers of respite care are sometimes paid only when spaces are used, they often find financial survival precarious.

Facilities used for residential programs should not also be expected to serve as centers for planned respite care and emergency services, which require a separate community base. The constant influx of new people is disruptive.

Respite care can also be provided in the

home, to allow care-providers a much-needed break in routine and duty. In our public forums, the single most frequent plea from families was for a reasonable amount (several hours a week) of in-home support. That level of support, many said, would enable them to carry out their responsibilities with renewed energy and enthusiasm.

Family support plans, in general, should be developed and coordinated by a single agency per family, and then updated annually.

Help Individuals with Additional Needs

Persons whose mental retardation is combined with one or more other disabilities—such as deafness, blindness, autism, maladaptive behavior, or head injury—are particularly affected by inadequate and inflexible services: the very citizens most in need of state assistance are left with families who do not have the resources to care for them effectively, or in nursing homes where training in basic living skills is extremely limited.

To ensure that this “extra-special-needs” group obtains what it needs, residential, day, and vocational program plans and budgets should always include specific provisions for appropriate access, accommodation, and integration. Special needs demand special attention, not a closed door.

Some elderly and medically-fragile retarded persons also require specialized services. Because of medical advances in the past twenty years, many retarded persons who would have died at an early age now live normal lifespans, and aging’s effects on them are sometimes magnified.

Because the relatively small population of multiply-disabled individuals is scattered throughout the state, it is often difficult to group the three or more persons from one DMH area required for most housing programs. Possible solutions include provisions for smaller-scale programs or programs within private homes or apartments. Bringing together participants from several areas or regions makes sense if enough multiply-disabled individuals decide that dropping the “area of meaningful tie” standard is worth the tradeoff. At the

Fernald and Wrentham schools, for instance, deaf clients are able to speak sign language daily with other clients and specially trained staff. The North Shore ARC (Association for Retarded Citizens) runs a similar regional program in a community setting.

The five state schools have an important role to play here. As their resident populations gradually decline in size due to community placements and deaths from age, the staffs’ experience with severe handicaps and their newly-renovated facilities make them excellent sites for “regional resource centers.”

These regional centers would provide for the residential and/or training needs of multiply-disabled and low-incidence individuals when this expertise is otherwise unavailable in the local community. They could also offer sophisticated backup to community programs in areas of health care, ongoing professional training, diagnosis and testing, emergency support, and demonstration projects. (The Templeton Farm Colony, for instance, is a unique program difficult to duplicate on a local level.) The state’s considerable investment in staff, land, and buildings for citizens with mental retardation should be preserved and put to creative use.

Train and Certify Direct-Care Staff

Regardless of structure, funding, or external monitoring, the welfare of persons with mental retardation is ultimately entrusted to direct-care personnel, who currently receive no uniform training. We recommend that the state license or certify all direct-care staff, public and private, to:

- ensure a minimum level of knowledge and training in the field;
- provide a mechanism for screening applicants;
- prevent the re-employment of those who are terminated for just cause;
- help “professionalize” the occupation;
- lessen the chance of physical and psychological abuse.

The successful completion of exit examinations after at least 40 hours of classroom

When a person is given a choice [about where to live], it should be that and not an ultimatum. People are living in the past when it comes to life at a state school. The people there are not locked up. They work five days a week like you and me and many get ready to go out at nights, whether movies, shopping, or dancing—the same choices that you and I have.

—Staff Member,
State School

I think the true test of the evaluation of Individual Service Plans is if the families, the clients, the legal guardians are pleased with the services they're receiving. I'd be tempted to put more stock in that feedback than any feedback received from the Department.

—Former Service Coordinator

training would entitle a trainee to a provisional certificate. After working under direct supervision for an additional three to six months, a trainee would be eligible for full certification. A master record of these certificates could serve as a screening mechanism for future employment.

Obviously, this sort of training cannot substitute for a caring attitude on the part of personnel, but it *can* establish consistent standards of behavior and knowledge throughout the state. The Task Force is sensitive to service providers' current staffing difficulties, but we see this requirement as a minimum protection for mentally retarded persons. In any event, the state, not the service provider, should offer this training and certification.

Coordinate Inter-Agency Services More Effectively

An important obstacle to services for mentally retarded persons today is the state's uncoordinated approach to entry into the system. The Departments of Social Services, Public Welfare, Public Health, and Mental Health; the Massachusetts Commission for the Blind; and the Massachusetts Rehabilitation Commission are all involved in the provision of services, but the mentally retarded individual (or his parent/guardian) has no clearly-defined avenue for help.

The agency staffs themselves, although they mean well, are often unaware of alternate, appropriate, and available services, and they are unable to make useful references. Service coordination, as a separate function within the Executive Office of Human Services and independent of DMH (or DMR; see discussion under "Structures" below), is one solution we see.

Today, Service Coordinators face a built-in conflict: while they are supposed to advocate for clients and obtain appropriate services, they are intimately tied to both funding procedures and DMH pressure to place clients in particular programs. They also have oversized caseloads (sometimes more than 60 clients) and varying responsibilities, depending on the area office in which they work.

We recommend that, in addition to the existing DMH service coordination system, an autonomous Office of Service Coordination (OSC) be established within EOHS, with a three-level (area/regional/central) structure matching DMH's. Additionally, the new Service Coordinators should be full-time state employees (02 category), and limited to a caseload of no more than 30.

These Service Coordinators would perform the initial entry evaluation of every person entering EOHS services, and for those identified as mentally retarded, prepare and supervise the Individual Service Plan (see below). Impartial and independent Service Coordinators would be able to avoid the communications breakdown and service fragmentation so common to needs which cross agency lines.

Some Task Force members, sharing the same goal, felt that focusing attention on better service coordination at the area DMH/MR level—where it exists now—was a more direct and effective approach than a new OSC.

Improve the Individual Service Plan (ISP) Process

ISP's, originally mandated by the consent decrees, now form the cornerstone of service delivery for mentally retarded persons in this state. Behind the ISP is the concept that each person needs a thorough, personalized evaluation of his or her needs and a regularly-updated prescription for a broad range of services. A cross-section of people from the retarded person's family, work, and residential spheres participates in planning meetings. Unfortunately, not every retarded person receives an ISP now, and there are flaws in the process itself.

As a first step, all persons evaluated as mentally retarded upon entry into EOHS should receive an ISP within 60 days—even if they need services not immediately available and are placed on a temporary waiting list. Because they define explicit needs and identify service gaps by number, type, and area, the ISP's as a group could function as the department's primary planning resource for the future. (This is also an ideal computer database application.)

Age-related transitions are unnecessarily bumpy. Although all retarded persons between the ages of three and 22 receive Individual Educational Plans (IEP's) through Chapter 766 programs, many are unable to obtain Individual Transitional Plans (ITP's), which can smooth their transfer into adult services, because of a shortage of Service Coordinators and funds. Also, IEP's often fail to include a record of non-school (recreational and social) needs, so the ISP must start from scratch in these areas. The participation of school representatives in initial ISP meetings should be a requirement.

The evaluation team, headed by a Service Coordinator, should review all ISP's semi-annually and update them annually, as well as before any major residential or employment transition. Continuity is important, too: any problems left unresolved in a previous ISP must be carried forward into the new document.

Secondly, the ISP process as it stands is vulnerable to administrative, bureaucratic, and ideological attack. At its worst, the ISP becomes nothing more than a checklist of currently-available services, rather than a document keyed to individual needs. In determining those needs, the client's preferences, and those of his or her family or guardian, must be given substantial weight. The programs must change to fit the person, not vice-versa.

Service providers often decide themselves which services will be written into an ISP, and unneeded services are sometimes added to justify a particular placement. Conversely, an identified need and recommended service may be dropped if current programs do not provide it. In these cases, the ISP gradually becomes worthless as an accurate individual record and planning tool.

We realize that efforts are already underway to improve the ISP process, and to involve families to a greater degree. Even so, the Task Force is concerned about protecting the ISP's impartiality, whether through a separate Office of Service Coordination or another mechanism within DMH/MR. ISP's are too critical and too hard-won to be allowed to erode in this way.

Create a Quality Assurance Function within EOHS

Quality assurance, as implemented, is a matter of compliance with written standards, but its true purpose is to ensure that universal needs—safety, comfort, health, growth, and opportunities for love and friendship—as well as needs individual to each person are being met. Because they are usually the best judges of this, family members and clients—to the degree they are able—should play a significant role in the quality assurance (QA) process.

Although quality is an implicit objective for most programs, it needs to be explicitly described, tested, and evaluated. No formal QA system is now in place, and as a consequence, program quality varies dramatically throughout the Commonwealth.

A QA program should include specific standards, controls, scheduled and unscheduled audits, and formal team evaluations. Standards must be set for space, environment, health, and safety; staffing numbers and qualifications; client needs and enrollment limitations; and program goals, goal-measurement, and methodology. Flexible standards will also accommodate growth-stimulating models.

We urge that, after an outside consulting firm develops a detailed QA plan with the input of clients and families, a carefully-selected vendor supply the QA function and report to the Secretary of Human Services—or to whatever level of state government is necessary to ensure the *independence* of quality assurance. In the interim, an in-house task force should develop temporary program standards and all Area Boards should conduct quality assurance audits of their programs every six months.

As part of the overall standard-setting process, the regional centers (now the state schools) should be accredited by AC-MR/DD or another organization with equivalent standards.

When that day arrives that we can close a place like Wrentham and get a better place in the community, I will be the first one standing up cheering. But we don't have it yet.

—Parent of State School Resident

FACTS & FIGURES

What is mental retardation?

The American Association on Mental Deficiency (AAMD) defines mental retardation as: *Subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in maturation, learning, social development, or adaptive behavior.*

Individuals are further classified into four groups on the basis of their IQ scores:

LEVEL	(IQ)	General US MR Popul'n (1979)	MA Community Services (1986)	MA State Schools (1985)
Mild	(51-70)	89.0	36	7
Moderate	(36-50)	6.0	35	14
Severe	(21-35)	3.5	18	31
Profound	(< 20)	1.5	14	8
Undetermined		-	5	-

How does mental illness differ from mental retardation?

The National Alliance for the Mentally Ill defines mental illness as "the term used for a group of diseases causing severe disturbances in thinking, feeling, and relating. They result in substantially diminished capacity for coping with the ordinary demands of life." Compared with mentally retarded persons, who have a diminished intellectual capacity, those with mental illness are usually of normal intelligence, although they may have difficulty performing at a normal level due to their illness.

In 1986, DMH served a total of 10,117 clients with mental retardation: 3,118 in the state schools, 400 in the Glavin and Hogan-Berry regional centers, and 6,309 in community-based programs.

What causes mental retardation?

Mental retardation may be caused by genetic abnormality or by environmental hazard before or after birth. Some environmental factors that are specific causes of mild retardation are:

- birth injuries
- various maternal infections transmitted *in utero*
- chemical substances (e.g., thalidomide)
- fetal alcohol syndrome
- post-natal infections (e.g., encephalitis or meningitis)
- head injury
- malnutrition caused by poverty

The causes of moderate to severe intellectual impairment can usually be traced to genes, infections, and diseases which create brain damage. Some genetic causes are:

- Down's Syndrome
- Fragile-X Syndrome
- Phenylketonuria (PKU)
- Tay-Sachs Disease
- Tuberous Sclerosis

Mental retardation directly affects as many people as blindness, cerebral palsy, and rheumatic heart disease combined.

Sources: DMH, Shriver Center, ARC-US



Funding

Although current overall funding for state mental retardation services is less than we would like to see, many of our recommendations in this area deal with the sources of funds, allocation decisions, and the way in which money is spent. Ideally, the funding stream should be a broadly diversified mix of public (federal, state, local) and private (for-profit, non-profit, home-based) *partnerships* providing both generic and specialized services.

Make funding more creative and diversified, fair and flexible, dependable and sufficient.

Creative and Diversified

1. *Explore alternative approaches for raising and saving money* such as: fees-for-service, cash stipends for families, client-owned housing, revenues from institutional resources (i.e., sale, lease, and multiple use of land and buildings), special incentives to service providers for innovative programs, and a state lottery targeted for human services. A *senior-level policy and planning group* within state government, with representatives from Administration & Finance, DMH, legislative committees, and

EOHS should study these and other creative ways to better match dollars with human needs.

2. *Encourage private initiatives and responsibility through state tax policy:* credits, deductions, and subsidies. Creative incentives aimed at businesses and families can help to provide the additional housing, training, social, and employment opportunities mentally retarded individuals need. The subsequent savings to the state will more than offset the loss in tax revenues.

3. *Use all possible Medicaid state plan options* to pay for needed care; minimize the use of waivers. At the moment, services are overly tied to federal Medicaid strictures and reimbursement policies. Some discretionary waivers allow for services to be delivered in the home, for instance, but waivers are cumbersome, uncertain, and time-consuming to obtain every three years. Much more can be done without waivers, particularly in the area of personal care, medically-related respite, and case management. Instead of waivers, we should modify the existing state program to meet our needs.

4. *Maximize the use of private insurance plans* to provide health services and long-term care for retarded persons. One possibility is the development of a health insurance pool for otherwise uninsurable mentally retarded and other disabled persons, not unlike automobile-liability insurance coverage for high-risk drivers.

5. *Tap the technological resources of the Commonwealth.* The EOHS might collaborate with the Board of Higher Education

I feel there should be a system where, if there is a child in need, the money should be tagged with the child to go along with him, instead of all kinds of vendors and services saying this one needs this much and that one needs that much.

— Parent

Many of our old community residences have furniture that was bought 10, 15 years ago that is dilapidated and ripped—and there's no money within the DMH budget for replacement.

—Service Provider

It's sad to say, but salary structures for many vendors force them to accept staff who can "walk, talk, and breathe." Please don't legislate an additional requirement without the funds to make it work.

—Service Provider

and the Massachusetts High Tech Council to develop devices to assist mentally retarded people to gain greater independence in jobs, communication, and mobility.

Fair and Flexible

1. *Distribute available resources more equitably and rationally.* Many mentally retarded persons in the state are served inadequately or not at all—witness the waiting list. Some areas can offer the services they need, while other areas are unable to.

2. *Invest dollars in people rather than programs.* Currently, the state funds fixed-budget programs into which individuals are placed—and often stuck until another funded program becomes available. If, as their needs changed, mentally retarded persons could express their preferences and shift their funding dollars to a more appropriate service, programs would begin, grow, alter, diminish, and end in response to client needs. Vouchers are one experimental approach to this problem.

3. *Pay direct care personnel fairly.* Community-based staff now receive considerably less than state employees in the schools and elsewhere. After much talk, the “parity gap” remains and needs to be eliminated. Pay should not depend on whether employment is in the private or public sector, as long as the duties are comparable.

4. *Allocate new resources sensibly,* as they are developed. As stated elsewhere in this report, the Task Force’s service priorities are:

- Programs which support individuals and families;
- Employment training leading to independent work;
- Greater depth and breadth of community-based services.

Dependable and Sufficient

1. *Make a lifetime commitment* to persons with mental retardation. Even though mental retardation is a lifelong, developmental issue, programs are still funded on a year-to-year basis, leading to uncertainty and fear, both for clients and their families. We need to begin planning for the long term, not just in terms of forecasts, but in terms of actual

commitments by the state to its mentally retarded citizens. Universal special education and compliance with the consent decrees have firmly established the principle of lifetime service plans; now that principle must be extended to the balance of those who need it.

2. *Raise standards and broaden services in community programs which encourage independent, integrated living* for mentally retarded persons and support their families. The most dependable support is self-support. In particular, because of their central importance, programs which lead to on-site, un-“sheltered” work deserve increased funding immediately. DPW’s Employment Training (ET Choices) and the Bay State Skills Corporation’s supported-work model point the way for DMR.

3. *Begin investing in a “rainy day fund.”* The state should build up a targeted reserve to maintain the continuity of services in the face of abrupt federal policy changes, economic recession, or other reductions or emergencies.

4. *Fund capital improvements adequately and separately.* Even in ongoing programs, inadequate provisions for capital improvements lead to a deterioration in facilities. Furniture replacement or roof repair, for example, presently comes out of a community-based program’s annual service budget, using dollars that should be reserved for clients. An improved budget approval process would allow capital improvements to be regular line items, independent of client services.



Structures

An administrative organization exists to support services efficiently, provide continuity independent of individual personalities, manage the flow of forms and funds, and plan for the future.

Let individuals' needs dictate administrative structures, and meet those needs at the community level.

Create a Department of Mental Retardation

Services for persons with mental retardation in Massachusetts are provided most often under the Department of Mental Health umbrella. We believe the time is overdue for a separate Department of Mental Retardation, on the same hierarchical level as DMH and reporting to the Secretary of Human Services. This is a long-standing need—the 1966 Commission recommended a similar restructuring.

The reasons are many:

- The needs of persons served under the “mental health” and “mental retardation” rubrics are substantially different. Although occasional overlaps occur—a mentally retarded individual, for example, might

require psychological counseling during a major life transition—they are generally unrelated. Mental retardation is not a treatable “mental illness” as the term is commonly used, nor is it attended by the same set of professionals. (See the distinction in the “Facts & Figures” box.) The opportunity for synergy is slight.

- Even if they were divided, the departments would still be the two largest agencies in state government. Each division now has a budget approaching \$400 million; DMH's total budget will be \$1 billion in several years. The scale is such that the needs of mentally retarded individuals, their families, and the local community are subordinate to the needs of a too-broadly-defined agency.

- Although the Division of Mental Retardation is located within DMH, clients receive services from a broad array of other human service agencies, including the Department of Education, the Department of Social Services, the Massachusetts Commission for the Blind, the Department of Public Welfare, and the Massachusetts Rehabilitation Commission. Each of these agencies has its own mission and priorities, and serving the needs of mentally retarded individuals is rarely uppermost. They also have area and regional structures which are inconsistent with each other and (except for DSS) with DMH, so that a client or advocate must often thread a maze to obtain a service.

We understand the risk, of course—that a new department would simply create another expensive layer of bureaucracy. We believe, though, that the existing structure responds

DMH is a mega-system, and it makes it very difficult, if not impossible, to monitor and evaluate what's going on. If you can't, the individual client or a certain percentage of them will suffer.

—Service Provider

inefficiently to the special needs of retarded persons, and that a separate agency with a clearly-defined mission could deliver these services more directly, comprehensively, and cost-effectively. It would also offer greater accountability to the Administration, Legislature, and Massachusetts taxpayers.

Support Area-Based Service Delivery with a Three-Tiered Structure

The new department (DMR) would have three administrative levels: central, regional, and area. As we defined each level's roles, we kept these goals in mind:

- Let individual needs dictate appropriate structures.
- Minimize the overlap of responsibilities.
- Couple responsibility to appropriate authority.
- Support system-wide planning and standards.
- Allow flexibility for area-specific services.
- Keep program planning close to the clients.
- Maximize the role of the area board.

1. **Area Office Level:** As the principal operating unit of DMR, the Area Office must strive to provide an array of services matched to the needs of people living in the area. To that end, the Office (together with the Area Board) will prepare and annually update a Comprehensive Area Plan, identifying areas of need; planned initiatives to meet those needs; required fiscal and physical resources; strategies for program development, implementation, monitoring, and evaluation; and accomplishments of the preceding year.

Each Area Office will also be responsible for:

- Innovative programs for unique local needs
- Competitive procurement of services from providers
- Service coordination
- Individual Service Plans
- Program monitoring
- Staff training and personnel administration
- Information and referral
- Transportation

Making up the related Area Board, established by the Area Office, will be knowledgeable family members, clients, educators, professional staff, non-paid vendor representatives, and at least one member appointed by the local governing body. The Board will review and approve budget requests, program changes, and vendor selections.

2. **Regional Office Level:** The Regional Office will provide input from the local to the central level, so that central policy better reflects local needs and initiatives. In addition, each Regional Office will have strong fiscal and program responsibilities for the areas:

- Specialized technical and clinical assistance
- Licensing/evaluation according to DMR standards
- Fiscal management and legal support
- Contract compliance
- Consolidation of area budget requests
- Appeals—ISP, human rights, and contract
- Staff development and training
- Program development (low-incidence and inter-area)
- Area management evaluation

3. **Central Office Level:** As we decentralize budget development and program planning, the Central Office's role becomes a critical one of standard-setting (personnel, QA, programs), philosophical leadership, resource analysis, policy articulation, and legislative relations. By producing a coherent menu of services and a blueprint for their development, the Central Office will ensure the consistent availability of programs across the state.

The Central Office will also be responsible for:

- Research and development
- Technical assistance to the field
- Long-range planning
- Budget consolidation
- Inter-agency service coordination
- Statewide needs assessments and database management
- Statistical/cost-benefit analysis of area programs
- Engineering
- Statewide community relations and MR education

We need to see ourselves in some way or another sharing the experiences of the people we serve, the people we work with, the people whom we are supposed to be accountable to in improving the quality of life.

—DMH Field Staffer



Awareness

Informing the general public about mental retardation takes two avenues: prevention and community acceptance. Both are critical and demand higher levels of effort.

*Prevent the incidence,
reduce the disability,
and minimize the
isolation of mental
retardation.*

Prevent the Incidence of Retardation

Few people realize that *half* of all cases of mental retardation are preventable. Massachusetts should take a leading role in raising the public's awareness. Both environmental and genetic factors can cause mental retardation. Each of these topics merits a full-fledged advertising campaign:

- Drug, cigarette, and alcohol use during pregnancy;
- Maternal infections (rubella, syphilis) transmitted *in utero*;
- Identification of parents in high-risk categories;
- Toxic lead exposure in older homes;
- Immunization against common childhood diseases, particularly measles and mumps;
- Child car safety seats to prevent head injuries.

This is not just "public relations;" it is a

practical, high-return state investment. Public education dollars which help to lower the incidence of retardation save the Commonwealth enormous sums over the lifetime of individuals. Not every case can be prevented, of course, but those which can be, ought to be, for both moral and pragmatic reasons.

The state should also work with its strong medical establishment and the Department of Public Health to increase communications through health-care professionals, and to sponsor fundamental research to determine more precisely the prenatal, birth, infant, and childhood risk factors surrounding mental retardation. The exact cause of retardation remains unknown in two out of three cases.

Reduce the Severity of Retardation When It Occurs

As the model for dealing with mental retardation has shifted from custodial care to active treatment and normalization in recent years, we have learned much about the untapped capabilities of retarded persons. Simultaneously, improved medical skills have enabled severely disabled children to survive into adulthood: the percentage living to the age of 21 has *doubled* in the past ten years.

Together, these trends mean that the service system must cope with more severe problems, provide more sophisticated help,

*If they can put
people on the
moon, then why
can't we put
people out in the
world? . . . I hope
you people will
keep working, and
someday there
won't need to be
any more
hearings.*

— Consumer

and still support the integration of retarded persons into their communities. Early identification and intervention is one answer, as medical treatment or remedial skill-building for special-needs children can help to offset mental retardation's long-term effects. This also means that more and different services will be needed in school and community settings, and that the medical community must be educated as well as the public.

Build Community Acceptance and Reduce Isolation

A key thrust of contemporary programs for mentally retarded adults is integration of their home, work, and social life into the community's. We know that, given adequate opportunity and support, it works.

In many communities, though, fear and misunderstanding about mental retardation make it difficult to build homes and find employment. Many people still attach a stigma to mental retardation and discriminate against retarded persons.

When well-run, integrated residences are located in neighborhoods, though, their day-to-day success almost always results in community acceptance. These neighbors, as "converts" to the principles behind this report, make the most convincing witnesses at town hearings where community homes for mentally retarded individuals are being debated.

Similarly, where private companies have taken the initiative in employing retarded persons in regular work settings, their stories should be the foundation of public and corporate education efforts. Newspapers, magazines, and television are generally on the lookout for positive feature stories, and the companies themselves benefit from the favorable publicity.

At the individual level, the best place to begin is in the elementary schools, before ignorance hardens into prejudice.

Molding and changing public opinion on any subject is a gradual process, but the stubborn myths which stand in the way of full participation must be dispelled before mentally retarded persons have truly equal opportunity.

Conclusion

These are the Long-Range Planning Task Force's recommendations concerning future policy toward the members of our state family who happen to be mentally retarded. The recommendations spring from our research findings, public hearings, and personal judgment and experience. Although not every member of the Task Force agreed with every recommendation, this report represents the consensus opinion.

We offer them in a spirit of cooperation, striving to keep the channels of communication open. Only by working with one another will we fulfill the vision we share for 1996.

Although we have charted a specific course to a vital destination, variations in the route are immaterial, as long as we know our current position and the direction in which we are traveling. The objectives of *integration, independence, support, acceptance, commitment, and choice* are far more important than the specific methods used to achieve them.

The members of the Task Force look forward to working with state officials in implementing these recommendations.

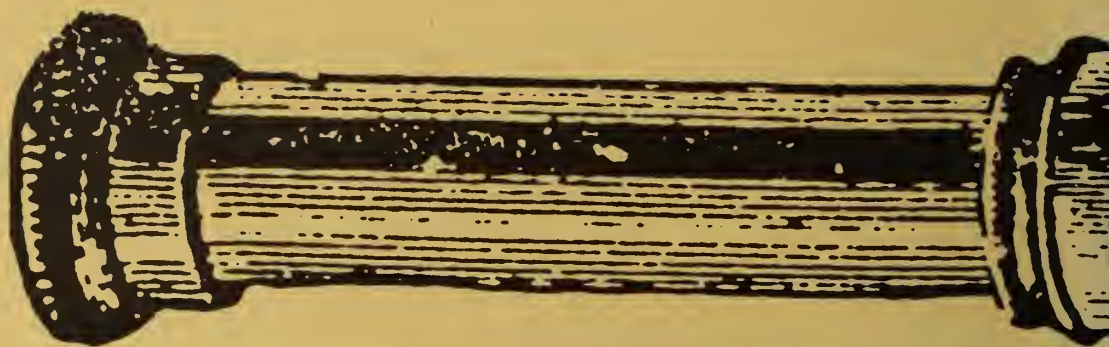
We had a vehement battle to locate a home in a local neighborhood two years ago. Six months later, the most vocal neighbor was inviting our clients for cook-outs in his backyard. It's fear of the unknown: What are these people going to be like when they move in? It's resolved when they are known on a person-to-person basis.

—Service Provider

A VISION FOR 1996

Ten years hence, we see a Massachusetts in which:

- Mentally retarded persons have access to a full spectrum of residential, vocational, educational, and health-service options.
- Every mentally retarded individual engages in ordinary life activities as completely as he or she is able and chooses to.
- Services in every setting are comprehensive, consistent, active, adequate, appropriate, and least-restrictive; and are evaluated regularly to ensure high quality.
- Persons with mental retardation are central in making decisions affecting their lives; can advocate directly for their rights; and are guaranteed long-term, stable service alternatives with professional coordination.
- Communities have learned to accept and encourage the presence and participation of retarded citizens; and cooperate in preventative measures to reduce the incidence of mental retardation.
- A child born with mental retardation is diagnosed promptly; provided with a comprehensive plan for long-term treatment, education, and care; and supported by a multi-disciplinary team of professionals, administrators, and family.
- A retarded adult is offered an individualized developmental reassessment at life's key transition points: leaving school, changing jobs or residences, dealing with a serious illness, retiring from work.
- Elderly retarded people whose physical and mental condition change have specialized supports and residential alternatives.
- Those responsible for the direct care of retarded people are paid wages which attract and keep good staff.
- Public resources are allocated to benefit those in most need of assistance; private resources are encouraged and supported by the public sector.



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